

**JOINT LEGISLATIVE OVERSIGHT COMMITTEE  
ON HEALTH AND HUMAN SERVICES**



# **Newborn Screening Update**

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# Newborn Screening

Newborn screening identifies conditions that can affect a child's long-term health or survival. Early detection, diagnosis and intervention can prevent death or disability and enable children to reach their full potential.

- North Carolina's newborn screening program began in 1966 as a voluntary effort, testing for one disorder - PKU
- The program became a legislative mandate in 1991 with the passage of "An Act to Establish a Newborn Screening Program"

# Newborn Screening is a System

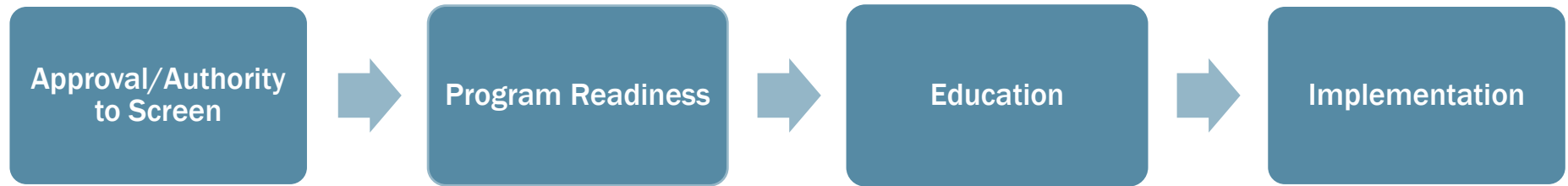
- Newborn Screening includes:
  - Screening
  - Follow-up
  - Diagnosis
  - Management
  - Evaluation
  - Education
- Adding disorders to the state's mandated panel requires the full system to protect newborns and their families

# 2018 Newborn Screening Legislation

- Enhanced the State's Newborn Screening Program
- New Conditions
  - Added three new disorders (X-ALD, Pompe, MPS-I) to the state's mandated panel
  - Established a process to add additional conditions from the national Recommended Uniform Screening Panel (RUSP)
- Financial Support
  - Address a historical structural program budget deficit
  - Build the infrastructure to initiate screening for new disorders
  - Support ongoing screening for new disorders
  - Fund program improvement initiatives

# Implementation is on Track

States who are currently screening for Pompe, MPS-I, and X-ALD averaged 26 to 45 months from first activity to statewide screening\*



To help expedite progress:

- Collaborating with other states
- Utilizing national resources
- Recently signed contract for 1st tier X-ALD equipment and supplies
- Competitive open bids in process for:
  - 2nd tier X-ALD instruments
  - Multi-tier screening method for Pompe and MPS-I

\*Data from NewSTEPs at ACHDNC April 2019

# Recommended Uniform Screening Panel

- **Spinal Muscular Atrophy (SMA)**
  - Only condition added to the RUSP since the 2018 legislation passed
  - North Carolina rule-making
    - Conducting needs assessment
    - Developing fiscal note
    - Preparing requisite documents
  - Anticipate draft rule submission to the Commission for Public Health in May